ALERT

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

SEPTEMBER, 1987

The UFMCC is pleased to introduce ALERT, a monthly newsletter designed primarily to keep our Clergy and Churches (as well as others involved in AIDS Ministry or service) informed on current information regarding AIDS legislation, education, research and treatment. We will also be sharing valuable program information and ideas from local churches. Monthly news in ALERT will be compiled and produced by Rev. Stephen Pieters, Gary McClelland, M.D. and Rev. Elder Don Eastman.

CDC BROADENS DEFINITION OF AIDS

It has been recognized ever since the discovery of the Human Immunodeficiency Virus (HIV) as the cause of AIDS and of sensitive, accurate tests to determine its presence that the original case definition of AIDS was far too narrow to include all of the manifestations of the disease. As a result, the statistics which are quoted so frequently in tracking the progress of AIDS have not been truly reflective of the full extent of the disease. In response to this awareness, the Centers for Disease Control in Atlanta, Georgia in its August 14, 1987 newsletter presented a new broader definition of AIDS which is expected to increase the counts by more than 15%. The stated objectives of this revision are:

1) To track more effectively the severe disabling morbidity associated with HIV infection.
2) To simplify reporting.
3) To increase the sensitivity and specificity of the definition.
4) To be consistent with current medical practice.

The major proposed changes apply to patients who are anti-body positive to HIV and:

1) have HIV encephalopathy (dementia), wasting syndrome (slim disease), or a broader range of specific AIDS-indicative opportunistic diseases than previously allowed.
2) have presumptive diagnosis of indicator diseases (formerly required definitive diagnosis).
3) have other causes of immunodeficiency (previously other causes excluded the diagnosis of AIDS).

While the primary goal of the CDC in introducing this expanded definition is for its own benefit - to reflect a more accurate picture of how widespread AIDS is - there is, a much more significantly beneficial impact of the definition on the AIDS patient and that is socioeconomic. Up to this point there have been a large number of people with significant illness, disability, and even death who were never classified as AIDS because of the narrow criteria which previously existed. Because these patients did not fit the AIDS definition they were excluded from many of the benefits which AIDS patients received (ie disability, SSI, MediCare, benefits from AIDS organizations, etc.). With the more realistic broadened definition of AIDS untold thousands will become eligible for these benefits and will no longer be living their lives in the grey zone - that limbo of disability in the absence of diagnosis.

If you would like a complete copy of the expanded case definition, please send your request with a self-addressed, stamped envelope to this newsletter.

HAVE YOU READ...?

AIDS: A SELF-CARE MANUAL by AIDS Project Los Angeles.

Editors: BettyClare Moffatt, M.A., Judith Spiegel, M.P.H., Steve Parrish, Michael Helquist. Santa Monica: IBS Press, 1987. Nine chapters of perspectives on living with AIDS, including "A Spiritual Perspective," "A Healing Perspective" and "Self-Care Resources," including AIDS-related Organizations and Hotlines in the U.S., Canada, England, France, The Netherlands, and Puerto Rico.

AIDS: THE SPIRITUAL DILEMMA by John E. Fortunato

San Francisco: Harper and Row, 1987. From the author of Embracing the Exile, a call for a spiritual response to AIDS. "He helps readers discover a redeeming spirituality through which they can transcend the crisis," (from the back cover.)

"PASTORAL CARE AND THE AIDS CRISIS" by Richard L. Schaper.

In The Christian Century, Vol. 104, No. 23; August 12-19, 1987.

SURVIVING AIDS: THE GOOD NEWS

The "Case Fatality Rate" for AIDS in the United States is NOT 100%, according to the June 22, 1987 AIDS Weekly Surveillance Report from the Center for Disease Control. In the first half of 1981, which is the earliest report of AIDS in the United States, 85 cases were diagnosed, of which there are 78 known deaths, giving a case fatality rate of 92%.

CASES OF AIDS AND CASE-FATALITY RATES BY HALF-YEAR OF DIAGNOSIS:

	NUMBER OF CASES	NUMBER OF KNOWN DEATHS	CASE-FATALITY RATE
1981 Jan-June	85	78	92%
July-Dec	180	161	89%
1982 Jan-June	365	318	87%
July-Dec	647	561	87%
1983 Jan-June	1217	1060	87%
July-Dec	1588	1338	84%
1984 Jan-June	2435	1949	80%
July-Dec	3192	2517	79%
1985 Jan-June	4352	3214	74%
July-Dec	5405	3592	66%
1986 Jan-June	6457	3388	52%
July-Dec	7056	2431	34%
1987 Jan-June 22	4332	951	22%
TOTAL	37386	21621	58%

While the CDC states that "reporting of deaths is incomplete," nowhere do they claim a 100% case-fatality rate, contradicting what is generally heard in the media.

An article in the September 6, 1987 Los Angeles Times profiles two long-term survivors of AIDS, Dan Turner and Michael Callen, who were both diagnosed in 1982. Callen is quoted from a speech to the American Public Health Association last year: "The unthinking repetition of the notion that everyone dies from AIDS denies the reality. But just as important, it denies the possibility of survival. It's hard to say which is the greater crime." Callen points to New York City Department of Health statistics, which reveal that 13 out of 100 Gay men with AIDS have survived at least four years past diagnosis.

In the same article, Dr. Martin Finn, medical director of the AIDS program for the Los Angeles County Department of Health Services, states that it is "entirely appropriate" for medical personnel to offer the examples of long-term survivors of AIDS to newly-diagnosed patients.

Some people are obviously living with AIDS far longer than the two year prognosis given by some doctors. And with the advent of AZT, experimental immunity boosters, and other new treatments for opportunistic infections, people diagnosed with AIDS will be living longer and longer.

WASHINGTON AIDS CONFERENCE HIGHLIGHTS

Michael Helquist, in FOCUS: A Guide to AIDS Research, August 1987, highlights two areas from the Washington conference: the implications of multiple studies regarding HIV antibody testing, and psychological issues for people with HIV infection, ARC, and AIDS.

Not surprisingly, those who tested positive showed increased depression, while those who tested negative showed lessening of depression. There was also the implications that all those who were tested showed "greater adherence to risk reduction guidelines than they did before being tested."

Test results and surveys reveal that even in "AIDS-sophisticated" urban areas of the world, a "small" group of individuals are still engaging in high-risk behaviors, and special educational "intervention" was called for. It was further pointed out that antibody testing seems to have a greater psychological than behavioral impact; while the experience of witnessing the consequences of AIDS was cited as a stronger motivator for change in behavior than knowledge of the facts alone.

In a survey of 30 people living with AIDS, conducted by the National Institutes of Health and Massachusetts General Hospital, it was noted that those surveyed found it "therapeutic" to openly discuss the impact of AIDS on their lives, that they appreciated health care professionals who were knowledgeable and who shared that knowledge, and those who showed acceptance, a non-judgmental attitude, and "concern about them as interesting persons." Patients were greatly concerned about confidentiality in all areas of treatment and service. Health care professionals were requested to "never take away patients' hope."

In other reports, the conference also heard a theory that, contrary to previous belief, HIV positive people become more infectious with time. Previously it was believed that seropositive people were most infectious shortly after their own initial infection with the virus.

Helquist also noted that physicians are more frequently recommending that HIV-positive people who have not yet developed any symptoms of AIDS should be given antiviral treatments, to prevent the development of AIDS.

Helquist was critical of the under-representation by people of color, gay men, and women among the presenters and participants. He also cited the lack of attention to AIDS in "less developed countries;" Western nations were given higher priority by presenters at the conference.

There were no reported major breakthroughs in treatments or vaccines, although Helquist noted an air of "cautious optimism."

NEW TREATMENT LOCATIONS

Nineteen medical centers around the United States have contracted with the National Institute of Allergy and Infectious Disease to conduct experimental protocols in the treatment of AIDS and related opportunistic infections. These programs are studying AZT as a treatment for HIV infection, as well as other new drugs for the treatment of pneumocystis pneumonia, Kaposi's Sarcoma and other infections associated with HIV infection.

Some of the current protocols are "AZT in Asymptomatic HIV-Positive Patients," "AZT and AIDS Dementia," and "AZT in the Treatment of Patients with Early ARC."

Following is a list of these AIDS Treatment Evaluation Units (ATEU's), including the names and phone numbers of contact persons:

Univ of Rochester Medical Center, Rochester NY 14642
Contact: Peggy Christy, 716/275-5871
Memorial Hospital/Memorial Sloan-Kettering Cancer Center, New York, NY 10021, Contact: Jill Leibel (PCP) 212/794-7900 or Denise Dundow (KS) 212/794-7426
Albert Einstein College of Medicine of Yeshiva Univ., Bronx, NY 10461, Contact: Lauri Vitagliano, 212/430-3659
Bellvue Hospital/New York Univ. Medical Center, New York, NY 10016, Contact: Mary Ann Kieman, 212/340-6565
Mount Sinai School of Medicine, New York, NY 10029, Contact: John Schalhoub, 212/650-8902
Massachusetts General Hospital/Harvard Medical School, Boston, MA 02114, Contact: Ellen Godfrey, 617/726-3812
Univ of Pittsburgh School of Medicine, Pittsburgh, PA 15261
Contact: Geraldine Tama, 412/621-3591 or 638-8719
The John Hopkins Hospital, Baltimore, MD 21205, Contact: Carol Hendricksen/Ed Fuchs, 301/955-2898
Duke Univ Medical Center, Durham, NC 27710, Contact: John Bartlett, MD, 919/684-5260
Univ of Miami School of Medicine, Miami, FL 31101, Contact: Janie Reese, 305/549-7323
Univ of Minnesota Health Sciences Center, Minneapolis, MN 55455, Contact: Su Reaney, 612/625-1462
Institute for Immunological Disorders, Houston, TX 77076, Contact: Mary Kilbourn, 713/691-3531 ext 247
Tulane Univ Medical Center, New Orleans, LA 70112, Contact: Jennifer Istre, 504/587-7316
Univ of Washington School of Medicine, Seattle, WA 98105, Contact: Ann Collier, 206/223-4756
San Francisco General Hospital/Univ of California, San Francisco, CA 94110, Contact: Doug Beardslee, 415/821-5531
Stanford Univ School of Medicine, Stanford, CA 94305, Contact: Virginia Tallman, 415/723-6231
Univ of California/Los Angeles School of Medicine, Los Angeles, CA 90024, Contact: UCLA AIDS Hotline 213/206-6414
Los Angeles County-Univ of So. Calif. Medical Center, Los Angeles, CA 90033, Contact: Yvonne Barranday 213/226-5225
Univ of California/San Diego Medical Center, San Diego, CA 92130, Contact: Candace McIvor, 619/543-6447

CHURCH PROGRAM FOR AIDS MINISTRY

In future issues of ALERT we would like to share what our churches are doing for AIDS ministry programming. If your church has a current program that you would like to share with the Fellowship, send it to:

Rev. Steve Pieters
UFMCC: ALERT
5300 Santa Monica Blvd., Ste 304
Los Angeles, CA 90029

Please make sure your descriptions do not exceed 350 words, and are presented in a legible manner.

FEEDBACK

We want ALERT to provide you with helpful information in a timely way. If you have suggestions or comments on how ALERT can be more useful to you, please write to Rev. Stephen Pieters at the address above.

1987 AIDS VIGIL OF PRAYER

Rev. David Farrell has been appointed by the Universal Fellowship to coordinate this year's AIDS Vigil of Prayer. Plans are to have a modified 24 hour Vigil to be held on November 7-8, 1987. Support materials are forthcoming; Rev. Farrell will be in contact with local UFMCC Churches soon. Rev. Farrell apologizes in advance for the lateness of materials, but states..."you know how it is!"

It is our prayer that many will be blessed from this effort and that you will see positive results because of your investments of time and energy, and because of your previous participation in last year's Vigil that you will have the support and an affirming response from the mainline churches in your area.

If the November 7-8 date is not convenient, churches are encouraged to select a more suitable date.

The Vigil of Prayer is in response to the Resolution passed by General Conference XIII in Miami Beach, Florida.

1987 SUPPLEMENTAL APPROPRIATION BILL PROVIDES FOR AZT

The AIDS Action Council has previously reported that an amendment appropriating $30 million for AZT is included in the FY 1987 Supplemental Appropriation Bill. On July 1, this appropriation bill was passed by both the House and the Senate and subsequently signed by the President. The Human Resource Service has set up a state by state distribution mechanism for these funds.

CLINICAL TRIAL UPDATE

During the Summer, the AIDS Action Council has been working with staff at the National Institutes of Health to increase the dissemination of information regarding the 19 drug trials currently underway in AIDS Treatment Evaluation Units (ATEU's) across the country. The Council has learned that at many of the ATEU's there are only a few people enrolled in many of the clinical trials. On June 24, AIDS Action Council Executive Director, Ann McFarren issued a press release regarding the drug trials currently being conducted by the National Institutes of Health and urged PWA's to contact the nearest ATEU for information about the drug trials that they may be eligible to participate in. Please contact the AIDS Action Council office in writing if you are interested in obtaining a copy of the press release.

AIDS Action Council
729 - 8th Street, S.E.
Washington, D.C. 20003
(202) 547-3101

FOR YOUR ACTION!

The AIDS Action Council has urged that two important actions be taken by local UFMCC people:

1) Contact your Congressional Representative to request that copies of the Surgeon General's Report on AIDS be mailed to every household in their district. A sample letter is included with this newsletter.

2) People coming to Washington for the National March can meet with their Congressional Representatives to discuss AIDS and AIDS-related issues in their home districts. The AIDS Action Council is coordinating this effort. If you wish to participate, please complete the enclosed form and mail to the AIDS Action Council immediately!

APPROPRIATIONS UPDATE

The House and the Senate have passed a 1987 Supplemental Bill which has several provisions for AIDS. The breakdown of these provisions is outlined below:

* $20 million for a house to house mailing of AIDS information and education materials

* $30 million to provide AZT for persons eligible under the labeling of the drug

* $20 million to expand state testing programs

* $7 million for targeted AIDS information to minorities

AIDS RESPONSE SURVEY

The UFMCC will conduct an AIDS Response Survey with all of its churches during the month of November. The survey will seek to identify needs and resources for AIDS ministry as well as assessing the present impact of the AIDS crisis on local churches.

Please watch for the questionaire and be sure your church participates in the survey. It is vitally important that all UFMCC churches be included.

POLICE DEPTS. HEAR FROM JUSTICE DEPT. ABOUT PEOPLE WITH AIDS

The US Justice Department's National Institute of Justice has encouraged police departments to formulate policies and training programs for officers who deal with people with AIDS. In a new report from the National Institute of Justice, law enforcement officers were informed of the limited routes of HIV transmission. The report teaches officers to counter misinformation, and points to already existent police department procedures which accurately reflect guidelines from the Center for Disease Control.

If you wish to read the full report, write the National Criminal Justice Reference Service, Box 6000, Rockville, MD 20850, and ask for "AIDS and the Law Enforcement Officer: Concerns and Policy Responses" (NCJ-105196).